



***Carers of People with Mental Illness and Comorbidity
Response to the Draft ACT Wide Comorbidity Strategy***

*Submitted to the Mental Health ACT
February 2010*

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Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We recognize the displacement and disadvantage they have suffered since European settlement. We offer our respects to their Elders, and celebrate the continuation of the Ngunnawal people's living culture.

Carers ACT sincerely thanks all Carers who have contributed to the research and consultation activities which inform its policy and representation activities.

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 caring families living in the Australian Capital Territory. These families provide ongoing care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to over 5,000 families through our counseling, information, respite support, education, social support and case co-ordination services. Our services were assessed in 2009 to meet HACC and NCCP accreditation standards at a level of excellence.

Carers ACT has a constitutional mandate to represent the voices of Carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All Carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

Carers of People with Mental Illness and Comorbidity

Background and General Comments

Carers ACT welcomes the opportunities provided by Mental Health ACT for carers to contribute to the development of an ACT wide comorbidity strategy for people with mental illness who are also at risk of or experiencing alcohol and other drug problems (AOD). Responses provided in this paper are informed by input from carers participating in the Mental Health Carer Representation Program run by Carers ACT and from issues raised by carers receiving support services from Carers ACT.

The draft strategy offers a good beginning point to generate a comprehensive, realistic and workable plan. Carers recognize that generic statements about facilitating greater cooperation are part of the strategy, but they consider it essential that Mental Health ACT demonstrates a strong commitment to the immediate and ongoing change in both practice and culture which will be required to achieve improved outcomes for both consumers and carers.

Carers strongly recognize the need for an appropriate comorbidity strategy to improve service delivery in the ACT. Carers supporting people with mental illness and AOD problems frequently report difficulties in obtaining access to support that appropriately meets the needs of the person they care for. They report often being caught in a gap between services; being told that the person they care for cannot be treated for the mental illness when intoxicated, yet cannot enter rehabilitation services until their level of mental illness is stable or controlled. An appropriate strategy is needed to better respond to the reality that increased usage can often be in response to worsening symptoms of mental illness and, vice versa, that an increase in AOD usage can have significant impact on experiencing symptoms of mental illness.

Carers also still report the need for improvement of systems of review. There is little awareness that Mental Health ACT has implemented a 'No wrong doors' policy of review for people with mental illness who are experiencing diminished wellbeing and/or an increase in symptoms. Carers ACT would be happy to support MHACT initiatives for improving awareness of this policy change. However, the strategy also needs to recognize that some consumers and carers face additional barriers to obtaining information, especially Aboriginal people, people from culturally and linguistically diverse communities, people with intellectual disabilities or cognitive conditions (such as Acquired Brain Injury) and people with literacy problems.

Purpose and Scope of the Strategy

The strategy needs to specifically include issues related to youth and services offered to youth within its scope. This would better recognize the high numbers of younger consumers and carers who are affected by issues of comorbidity. Major proportions of young people with mental illness are already experiencing, or are particularly at risk of, AOD problems.

There is also a very high degree of young people who have an ongoing involvement with comorbidity; as friends, as siblings, as partners, or as children of the person experiencing mental illness and AOD. It is vital that any strategy, especially one based around principles of early intervention and prevention, appropriately addresses issues of proximity and risk. Young carers looking after someone with comorbidity are particularly vulnerable to negative outcomes from the impact of their caring role, are more likely to be socially isolated due to poverty and stigma, and often face additional barriers in accessing supports.

There is also need for the strategy to recognize that gambling addiction is an issue of significance which is often associated with alcohol and other drug problems. Consumers and carers need information on pathways to support, where support can be incorporated into treatment and care plans for the comorbid mental illness and AOD condition.

Improving Care for People with Comorbid Conditions

- **Drug Induced Psychosis**

Carers indicate that there needs to be a better general understanding of drug induced psychosis. They have expressed needs for improved information on drug induced psychosis, recognizing symptoms, how drug induced psychosis can be treated, and what are the pathways to receiving treatment in the ACT and regional area. They state that this information would help them to better understand the condition, help them work with the broader treating team (such as AOD services and general practitioners) and help them provide appropriate information to enable improved understanding and support from other family members and friends.

Some carers have also called for improved understanding of drug induced psychosis across all levels of staff in general mental health treatment and care environments. This is needed because they report experiences where they have received confusing or conflicting information from staff, or have encountered insufficient awareness of issues to do with drug induced psychosis among staff working in a mental health care environment.

- **Nicotine Addiction and Smoking Behavior**

Carers consider nicotine addiction and smoking behavior to be a problem of sufficient negative health impact to be included under the strategy. Many carers report perceptions that smoking tends to be ignored by mental health treatment and care services 'as there are more important clinical issues to deal with' and also considered that many staff facilitate smoking behavior as a normative 'coping' strategy which is to be expected of consumers. Some carers have even reported that the consumer was a non-smoker when admitted to a mental health facility, but was a smoker by the time of discharge.

Impacts of smoking behavior go beyond the health implications, as the cost of smoking overshadows all other priorities for the consumer. They see cigarettes as more important than other things which will promote long term

health such as good nutrition and this can create problems for the carer. For example, the family or carer may refuse to pay for cigarettes for the consumer, but will find that they are indirectly supporting the habit as the consumer will not buy food or pay rent and other bills, and the carer cannot in good conscience let them go hungry or become homeless.

- **Physical Health and Nutrition**

Carers would also like to see the strategy promote long term pathways for consumers that involve all aspects of care. Carers frequently report that mental health services fail to adequately recognize the physical health needs of consumers, including access to medical care for non-mental health issues. They also consider that there needs to be greater integration of health promotion strategies such as the need for good nutrition, dental care and personal hygiene to improve levels of preventable illness in consumers.

Nutrition is critically important when dealing with AOD problems, as drug and alcohol use often leads to a reduction in nutrition stability – both from the poor diet choices made by the consumer and from the toxicity effects of the alcohol/drug on the metabolism. Again, carers need greater support in dealing with nutrition management issues related to AOD as they often find themselves indirectly supporting the cost of AOD by supplying food to the consumer.

Consumers who do not have good insight into their own mental illness may also benefit from strategies which promote greater integration of mental and physical health. There are a number of non-mental health services which have frequent contact with mental health consumers, such as community health teams looking after wound care, yet these services are effectively delivered in isolation from the mental illness. Better service awareness of both the AOD and mental illness issues could see the adoption of different strategies for healthcare, which could have a better rate of success and improve outcomes for consumers.

- **Case Coordination and Case Management**

Carers consider it vitally important that consumers are better supported by a mental health treatment and care system which focuses on early intervention (at first diagnosis and at onset of episode) and prevention. Carers feel that the current system of mental healthcare is focused on crisis response, leaving it difficult for consumers to get appropriate care when becoming unwell until they reach crisis point. Severity of episode can adversely affect the length of time needed to achieve stability and/or recovery.

Carers recognize that many consumers need a higher level of support to achieve recovery than is provided through case coordination services. Carers consider that case management needs to be more accessible and flexible. Carers have reported that if there has been a number of months between crisis episodes, they have found that the consumer's case has 'dropped off the list' for the previous case manager and they are advised that they have to join the waiting list from the beginning again. Greater long-term support is also

needed to help consumers achieve more independent and stable levels of functioning.

Carers are often forced into a defacto case management role due to shortages in available supports. Yet, such a role can have a negative impact on the carer and can contribute to the breakdown of family relationships. Demands on carers and families can be financial, emotional and physical, depending on the complexity of the consumer's condition/situation and the availability of other natural supports. Case management can place a significant additional workload on the carer, especially when multiple agencies or services are involved in treatment and care.

Improving Supports for Carers of People with Comorbid Conditions

- **Keeping Families Connected**

Carers need access to appropriate supports which recognize the special needs of people who have a comorbid mental illness and AOD problem. Carers ACT offers a psycho-educational course *Keeping Families Connected* which is open to families of a person with comorbidity. Carers ACT also offers access to counseling, respite and social support services to better assist carers in their caring role.

- **Carer Vulnerability**

Carers ACT recognizes that the high levels of stress involved in providing care for a person with a comorbid mental illness and AOD problem can lead carers to be more vulnerable to both mental illness (particularly anxiety conditions and depression) and AOD problems. Improved education and awareness helps to promote understanding of these risks in carers and encourages them to seek increased support if needed. The strategy also needs to ensure that carers are quickly identified by treating professionals and referred to appropriate pathways for support.

The strategy also needs to better recognize the issues surrounding family violence that are frequently evident when someone has a mental illness and a comorbid AOD problem. Carers and consumers need appropriate pathways for support with family violence.

- **Carer Inclusion**

Carers consistently report that they still experience barriers to inclusion in the treatment and care of consumers with mental illness. It is critical that carers receive generic information and advice from treating professionals, even in cases where a consumer has refused permission for the carer to be directly involved in their treatment plan. Greater education is needed to enable both carers and treating professionals to understand the level of information that can be provided in such circumstances.